

Communication challenges and helpful strategies for the person with dementia

Alzheimer *Society*

Day to Day Series

Communication is an important part of our life; it helps us to express who we are and allows us to relate to one another. When we communicate, we exchange information about our needs, opinions, ideas, beliefs, feelings, emotions, experiences and values. Communication is more than talking and listening; it involves understanding and interpreting.

As you live with dementia, it is not uncommon to experience changes in your communication abilities. You may notice that sometimes you cannot find the right word, or that you need more time to express how you are feeling. Even though communication challenges will arise, it is important to remember that communication remains possible at every stage of the disease.

Some of the communication changes that you may experience include:

- Creating new words for ones that are forgotten
- Repeating or getting stuck on a word or phrase
- Finding the right word
- Reading and writing
- Reverting to the language that you first learned
- Losing your train of thought more often
- Expressing yourself
- Understanding the words heard
- Difficulties following instructions with many steps
- Staying on topic

Dementia may also cause sensory changes, such as hypersensitivity to noise and certain tones. Changes in the senses may make it difficult to interact with your environment, and to communicate with others. Because of this, it is important that you have regular hearing and eye exams and that you wear glasses and hearing aids, if needed. If you wear hearing aids, check batteries regularly.

All of these changes can be upsetting and frustrating for you and for those around you. Remember to be kind to yourself. In this information sheet you will learn strategies that you can use to support your communication with others.

Communication strategies

Talk about your wishes and plans for the future:

- At the early stages of the disease, you should use communication to your advantage. This is a good time to start talking about your wishes and making them known.
- Talking about your wishes with trusted friends and family members when you are still able to do so can give you a sense of control over your future and put your family more at ease.
- It is also helpful to write your wishes down and revise them regularly to make sure that they reflect what you want.
- Be sure that someone trustworthy has the legal authority to make financial and healthcare decisions for you when the time comes.
- Advice from lawyers and/or financial consultants can also be helpful. You can tell them how you want to be involved in decision-making.

Learn about the disease and being open about it:

Learn as much as you can about dementia. Be open with your family and friends about your diagnosis and share your feelings and experiences as much as you are able. Let family and friends know that you may need more time to express yourself and if you are tired or have difficulty communicating, encourage them to speak with you when you are more rested.

Communication challenges when in social situations:

When you are having conversations with other people you may find it difficult to stay on topic, or follow a conversation. When this happens, try not to feel intimidated or embarrassed. Take time to relax and think about what you want to say. When in a social situation, consider using the following strategies:

- Ask people to slow down, use short sentences, or repeat what they have said.
- Write down one word that can bring the point back when you get an opportunity to speak.
- Tell people how you would like to be helped. Some people with dementia say they like to have time to find the word or answer they are looking for, while others appreciate if someone fills in the words for them.
- If too many conversations or too much noise bothers you, find a quiet place.
- If you lose a thought, let it go – it is okay if you forget it – it may come back.
- Take your time.
- Tell people you sometimes have problems with thinking, communicating and remembering.

- Be a good friend to yourself. Treat yourself with the same kindness and patience you would show others.
- One-on-one discussions are usually easier than keeping track of conversations in large groups.

Using non-verbal communication:

As the disease progresses, non-verbal communication will become very important. Non-verbal communication includes writing, gestures, signs or signals, behaviours and displays of emotion. To help you communicate with others, consider using:

- Notes for reminders of what you would like to share with others.
- Visual aids or non-verbal cues, such as drawing pictures or using hand signals to indicate that you need help with something.
- Your eyes, gestures and body-language to enhance communication.
- Laughter. Laughter is a good way to communicate to others that you are at ease and it will make them more open to what you are sharing.
- A mobile device (e.g., tablet) for when you want to record your thoughts.
- A computer or tablet to write letters to others. You can also use the computer to help you proofread.

Communicating with your doctor or another healthcare provider:

When visiting your doctor or another healthcare provider, you may experience difficulty remembering questions that you wanted to ask. Your visits may seem rushed, with little time to express your symptoms and concerns. When communicating with your doctor or another healthcare provider, consider using the following strategies:

- Try booking extended appointments, when possible, so you don't feel rushed. This will give you enough time to express yourself and talk about your challenges.
- Prepare for your visit by writing down symptoms and any questions you may want to ask. You may want to focus particularly on the things that have changed since your last appointment.
- To feel at ease, you may want to ask a friend or family member to accompany you to help communicate and clarify information.
- Be honest and open with your doctor or healthcare provider about everything that has changed.
- Be as specific as possible.
- Ask them to explain things to you in a way you can understand and to write down every instruction for you, no matter how small it is.
- Ask them to talk to you directly.
- If you are unhappy with the way they treat you, let them know how you feel.
- Finally, when it comes to your health and your feelings, you are the expert!

Remain socially active and try not to isolate yourself. Sometimes, as the disease progresses and communication skills change, getting out and meeting people – or even having visitors – can seem like too much effort. Contact the Alzheimer Society of Toronto for support, information and strategies to remain active. You may also want to join a support group to talk with people who can understand and relate to what you are going through. This will allow you to share your feelings, your challenges and coping strategies with others.

Consider contacting a speech-language pathologist. Speech-language pathologists are specialists in the area of communication and can help diagnose and treat language issues. They can teach you strategies to help you communicate. For individuals diagnosed with primary progressive aphasia, the support of a speech-language pathologist is particularly important, as the person will experience a progressive loss of communication abilities. To find a speech-language pathologist near you, please visit: www.sac-oac.ca/find-speech-language-pathologist-or-audiologist-service or ask your doctor to make a referral.

Although dementia may affect your communication skills, remember that communication is possible at every stage of the disease. While you are still in the early stage of the disease, use communication to your advantage and let others know how you are feeling. If you are having communication difficulties, try the strategies found in this sheet to help you communicate with others.

For more information on adjusting to changing abilities, contact the Alzheimer Society of Toronto or visit our website at www.alz.to

Information and support are available. You are not alone.

The contents of this document are provided for information purposes only, and do not represent advice, an endorsement or a recommendation, with respect to any product, service or enterprise, and/or the claims and properties thereof, by the Alzheimer Society of Canada. The information sheet is not intended to replace clinical diagnosis by a healthcare provider.

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